Towards adequate care for sexual health and fertility in chronic kidney disease: Perspective of patients, partners and care providers

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7. The implication of end-stage renal disease and sexual dysfunction on relationships; the perspectives of patients and partners.

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Introduction

A little over 11% of the world population is confronted with end-stage renal disease (ESRD) (1, 2). Patients with ESRD encounter challenges in several life domains. In addition to physical impairments (e.g. anemia, bone disease, and neuropathy), psychosocial well-being is often affected (2, 3). Because of an increase in long-term survival due to improved treatments, including dialysis and renal transplantation, a shift towards psychosocial well-being is forced (4-6). During dialysis, depression, health concerns, and social isolation are known stressors among patients (6). In addition, great challenges in the relationship between patients and their partners could arise (4, 5). A patients' dependency on care and responsibilities that their partners may need to provide could alter roles within the relationship (4, 5). When patients reach the phase of renal transplantation they may still face psychological problems due to this life-changing event (7). After renal transplantation, patients often acquire new energy and are no longer dependent on others as they were before, a new balance and new roles within the relationship need to be found (8, 9). Due to a shortage of organ donors, patients are more likely to receive a living donor kidney from a relative or their partner. After receiving the transplant, relationships may change and deteriorate as patients feel they owe the donor for the organ or are afraid to disappoint if they lost the graft (10). During the whole course of ESRD, relational challenges could also arise on a more intimate level. Sexual dysfunction (SD) is associated with dialysis treatment as well as renal transplantation (11-13). SD can be a result of both physical (e.g. hormonal disturbances) and psychosocial factors (e.g. changes in body image) with a prevalence in up to 70% in patients undergoing dialysis and 60% in transplant recipients (7, 11-14). In men, erectile dysfunction and anejaculation occur, whereas women experience pain during intercourse and a decrease of vaginal lubrication (11, 13, 15). Their partners do not remain unaffected; 50% experience sexual issues as well (16).

Being diagnosed with ESRD, starting with dialysis or being confronted with renal transplantation are all major events in the lives of patients and partners, and are sometimes aggravated by the presence of SD. A stable and good relationship can enable them to cope with these life-changing circumstances and the attached health concerns (4). This cross-sectional pilot study aimed to evaluate how the relationship between patients and partners is impacted by ESRD, dialysis or renal transplantation, and SD.

The perspective of both patients and partners were assessed by focusing on self-reported impact and relationship features such as perception of mutual support. In addition, the associations between the type of treatment (dialysis or renal transplantation) and the level of relational impact was examined.

Methods

Participants

This project was initiated in July 2016 and the last participants were included in July 2017. Participants were diagnosed with ESRD and were undergoing dialysis or had received a renal transplant. Invitations to participate were distributed among all patients who received dialysis at the Leiden University Medical Centre (LUMC, n=73), Haga Hospital (Haga, n= 108) or Haaglanden Medical Centre (HMC, n=139), and if applicable their partners. Participants who received a renal transplant were recruited among all patients that received either a kidney or a combined kidney-pancreas transplant in the LUMC between July 2014 and July 2016 (n=257). Partners received a request to participate as well. Participants were eligible to participate if they were aged 18 or older, if they were in a relationship, and were able to complete a questionnaire in English or in Dutch. If patients declined participation, their partner could still be included and vice versa.

Procedure

An envelope containing two information letters and two informed consent forms, one for the patient and one for the partner, were distributed either by mail or in person by a nephrologist or nurse during the morning rounds. If written consent was provided, a questionnaire was sent to the home address of the participants. Patients and partners received separate questionnaires, sent to them in separate envelopes. A reminder was sent after four, eight and/or sixteen weeks if patients and partners agreed with participation, but did not return the questionnaire.

Instruments

This study was conducted with the use of self-designed questionnaires. The design was derived from previous research projects conducted by the research group, the content was based on literature and expert experience.

Themes addressed in the surveys were (i) the self-reported impact of ESRD, dialysis or renal transplantation, and sexual dysfunction on relationship, and (ii) perceptions of mutual support during ESRD and with sexual dysfunction.
All questionnaires contained items evaluating sexual care during dialysis or after transplantation as well, those questions were processed separately.

Privacy
All data of participants were stored and handled according to the Personal Data Protection Act of the Dutch Law. To secure anonymity, all personal data were encoded; only the first author possessed the key to this code.

Ethical consideration
This project was conducted conform the guidelines of the Medical Research Involving Human Subjects Act (WMO) as was affirmed and approved by the institutional review board of the LUMC.

Statistics
IBM SPSS Statistics 23 (SPSS Inc., Chicago, IL, USA) was used. To test if age, relationship duration, and impact of SD on the relationships were normally distributed, the Shapiro-Wilk test was used. Independent t-tests were used to compare participants treated with dialysis and renal transplantation, with regard to age and relationship duration. Possible associations between gender, two different types of treatment (dialysis or renal transplantation) and changing roles within the relationship and self-reported impact were calculated using the Chi-square Test and the Cochrane Armitage Trend-test. A p-value of <0.05 was considered statistically significant.

Results

Response
Of the 577 patients invited to participate, 38 (7.0%) answered affirmatively and met the inclusion criteria. Twenty-eight partners were included.

Demographics
Almost three-quarters of the participants went through the process of renal transplantation; 73.7% of the patients and 67.9% of the partners. Ten patients received dialysis (26.3%); 9 of their partners (32.1%) participated

in the pilot as well. The mean age of patients was 62.9 years (SD 12.0) and partners was 60.4 years (SD 13.0) old. Participants receiving dialysis were significantly older than renal transplant recipients (p=0.002). Table 1. shows the sociodemographic characteristics of patients and partners.

Table 1. Demographics and disease specifics of patients and partners

	Patients (n=38)	**Partners (n=28)**
Gender n (%)		
Male	29 (76.3)	9 (32.1)
Female	9 (23.7)	19 (67.9)
Age (years)	62.9 (SD 12.0)	60.4 (SD 13.0)
Relationship status n (%)		
Living together	5 (13.2)	
Partner, not living together	5 (13.2)	
Married	28 (73.7)	
Level of education n (%)		
None – primary or basic	3 (7.9)	3 (10.7)
Lower general secondary Education	5 (13.2)	7 (25.0)
Intermediate Vocational Education	9 (23.7)	6 (21.4)
Higher general Education	2 (5.3)	0 (0.0)
Pre-university Education	0 (0.0)	1 (3.6)
Higher Vocational Education or Academic	19 (50.0)	10 (35.7)
Employment status n (%)		
Working	9 (23.7)	14 (50.0)
Not able to work because of disease	8 (21.1)	1 (3.6)
Retired	18 (47.4)	8 (28.6)

Other[a]	3 (7.9)	5 (17.8)
Duration of disease n (%)		
0-5 years	8 (21.1)	
5-10 years	10 (26.3)	
10-15 years	7 (18.4)	
>15 years	11 (28.9)	
Current stage of disease		
Dialysis	10 (26.3)	9 (32.1)
After renal transplantation	28 (73.7)	19 (67.9)

Note: n may differ due to some questions that were skipped or forgotten
[a] Including e.g. housewife and searching for work

Relationships and sexual health

The majority of patients (81.6%) were in a relationship when they were diagnosed with renal disease. The average relationship duration was 31.3 years (SD 16.0). The relationship duration in the dialysis group was longer compared to the transplantation group (mean 45.4 ± 13.1 vs. 27.0 ± 14.4 years, $p<0.01$). All patients were in a heterosexual relationship, except one. According to 22.9% of patients and 35.7% of partners, roles changed within the relationship due to ESRD. Partners of patients in the dialysis phase experienced these changes more often compared to those in the transplantation phase ($p=0.02$). Thirteen percent of patients and 19.2% of partners answered that they would have liked to have professional help with relationship issues. When focusing on sexual health, 65.8% of patients experienced sexual issues during the course of disease. Almost 50% of the patients (48.6%) discussed the possibility that the sexual issues were due to ESRD with their partners.

Self-reported impact on relationship

The self-reported impact of ESRD, treatment, and SD on the relationship between patients and their partners is shown in Figure 1. Most patients and partners stated that ESRD (reps. 58.3 and 50.0%), dialysis or renal transplantation (resp. 61.1 and 55.6%) or SD (resp.51.4% and 39.3%) had not affected their relationship. Male patients experienced more impact of

ESRD on their relationship then female patients (Linear by Linear Association, p=0.03); no associations were found between type of treatment and SD according to partners. In addition, no association was found between disease stage (dialysis or renal transplantation) and the level of reported impact from ESRD, treatment, or SD by both patients and partners.

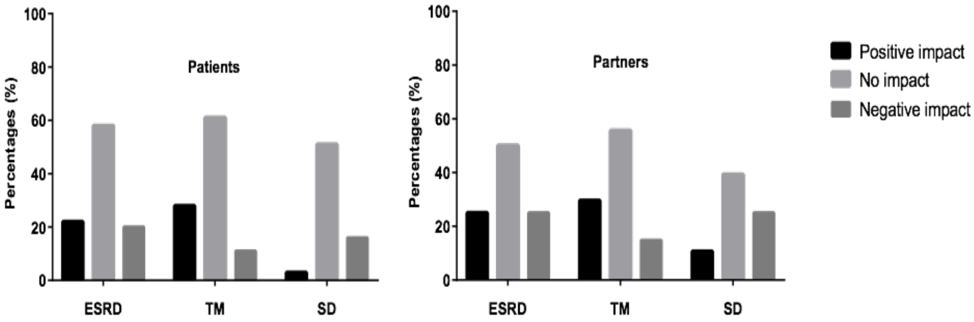

Figure 1. The self-reported impact of end-stage renal disease, treatment, and sexual dysfunction on relationships
ESRD: end-stage renal disease, TM: dialysis and renal transplantation, SD: sexual dysfunction

Support

Table 2 shows the support between patients and partners during end-stage renal disease. Both patients and partners were asked about their perceptions regarding mutual support during ESRD and SD with sexual problems, if applicable. Taking care of the patient during the course of ESRD was often mentioned by both patients (42.1%) and partners (53.6%). Regarding support for the partner during ESRD, both patients (50.0%) and partners (63.0%) mentioned continuing doing fun things. When focusing on mutual support when experiencing SD, both patients and partners agreed that continued intimacy within the relationship was the best form of support (percentages ranging from 38.5% up to 44.4%).

Table 2: Support during end-stage renal disease

	Patient n (%)	Partner n (%)		Patient n (%)	Partner n (%)
The best support regarding ESRD for the patient			**The best support regarding ESRD for the partner**		
To take care of me/my partner, if needed	16 (42.1)	15 (53.6)	To continue doing as many fun things as possible	19 (50.0)	17 (63.0)
To join all hospital visits	12 (31.6)	17 (60.7)	To stay actively involved	17 (44.7)	20 (74.1)
To start the conversation about ESRD	9 (23.7)	13 (46.4)	To start the conversation about ESRD	11 (28.9)	13 (48.1)
To search for information about treatment/ESRD	2 (5.3)	2 (7.1)	To ask (my partner) for as little care as possible	10 (26.9)	3 (11.1)
I do not know	11 (28.9)	3 (10.7)	To take my (partners) wishes into account	9 (23.7)	3 (11.1)
			To search for information about treatments/ESRD	0 (0.0)	2 (7.4)
			I do not know	7 (18.4)	0 (0.0)

The best support regarding sexuality for the patient			**The best support regarding sexuality for the partner**		
Do not lose intimacy within the relationship	14 (38.9)	11 (44.4)	Do not lose intimacy within the relationship	14 (40.0)	10 (38.5)
Not putting pressure on sexual intercourse	7 (19.4)	10 (40.0)	To involve my partner/me	8 (22.9)	5 (19.2)
To reassure when sexual intercourse is not possible	6 (16.7)	5 (20.0)	To start the conversation about sexuality	7 (20.0)	5 (19.2)
To discover other ways of being intimate	6 (16.7)	3 (12.0)	To discover other ways of being intimate	6 (16.7)	6 (23.1)
To start the conversation about sexuality	4 (11.1)	3 (12.0)	I do not know	8 (22.9)	5 (20.0)
I do not know	8 (22.2)	4 (16.7)			

Note: n may differ due multiple answers that could be given and some questions that were skipped or forgotten

Discussion

This cross-sectional pilot study presents data about the relationship related effects of ESRD and its implication on the lives of patients and partners. Evaluating both perspectives, the present study implies that, luckily, a negative effect of dialysis or renal transplantation on the bond between spouses is seldom reported. Similar results were found by Morelon et al. 2005 and White & Grenyer 1999; both described mostly unaffected relationships despite the tremendous impact of ESRD on daily life (6, 17). Sometimes ESRD and its necessary treatments were even described as a bonding experience, as also implied by a current pilot outcomes (6, 17). This bonding was identified when focusing on support as well. Most perceptions of support during ESRD were similar between patients and partners. However, some were uncertain when addressing the support they needed if sexual dysfunction was present. Nonetheless, these uncertainties, as well as the presence of sexual problems did not seem to negatively impact the relationship. Sexual dysfunction can be a deteriorating factor in the well-being of patients and partners, both during dialysis and after renal transplantation (16, 18-20). Current literature describes an association between relational discord and a decline in sexual intercourse in marriages confronted with renal transplantation (21). On the other hand, similar to the current outcomes, Raggi et al. 2016 and White and Greyner 1999 outlined sexual dysfunction as a burden for both ESRD patients and partners, yet a good relationship was able to be maintained (5, 6).

In spite of the perceived relational stability, one should not underestimate the impact of constant concerns regarding patients' health. Patients' health and disease are often a guiding themes in everyday life, especially for partners (22). During the course of ESRD, partners could be consumed by the care they need to provide for their spouse, often jeopardizing their own health (22, 23).

Incorporating a holistic approach to renal care when assessing relationships and caregiving for both patient and partner might be beneficial for disease and treatment outcomes (4, 6, 22). In order to facilitate this care more research should be conducted, especially on large and (inter)national scale, so an evidence-based design of psychosocial health care could be provided.

This study had a couple of weaknesses. As one of the first exploring relationships among both patients and partners confronted with ESRD, extensive formal comparison with literature was not possible. This study is mostly limited by response and selection bias due to its low response rate and the descriptive nature of the analysis. The low response might be a result of the overload of research performed among patients in ESRD on the one hand, and the severity of the illness on the other. In this light, outcomes should be interpreted as explorative and preliminary. In addition, no validated questionnaires were used as none exist assessing all study aims. The self-reported character of the study could have caused over-or underestimation since social desirable answer could have been given.

Conclusion

The impact of ESRD, dialysis, renal transplantation and sexual dysfunction on patient-partner relationships seems to be limited according to this pilot study. Yet, approximately a quarter of both patients and partners experienced changed roles within their relationship after confronted with ESRD. Perspectives on support during ESRD were quite similar between spouses.

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